

CONSULTATION QUESTIONS

Are you responding *primarily* as a data custodian, data user or data subject? (*We recognise all people are data subjects and many organisations act as data guardians and data users, but please tick only one box*)

Data Custodian

Data User (e.g. researcher)

Data Subject (e.g. member of the public or group representing citizens)

1. Are there any benefits of data linkage for statistical and research purposes that are not sufficiently described here?

Yes, there are further benefits No, the benefits are described fully

If you ticked 'yes', please describe the further benefits of data linkage for statistical and research purposes.

We think that more explicit mention should be made of the potential benefits of linking data on outcomes or service usage to protected characteristics in the Equality Act e.g. disability, ethnicity, sexual orientation. This is an important means of assessing the extent to which people with protected characteristics are disadvantaged or experience poorer outcomes than others.

2. Are there challenges or barriers preventing more effective and efficient data linkages for statistical and research purposes taking place that are not sufficiently described here?

Yes, there are further challenges No, the challenges have been identified

If you ticked 'yes', please describe the challenges or barriers.

Certain data sets such as those held by territorial health boards or local authorities have multiple custodians. Thus, data linkage for a national data set often requires permissions to be granted by at least one data controller in each health board or local authority and in some cases, by multiple data controllers e.g. every general practice. This can result in extremely time consuming processes for seeking permission. If some permissions are denied, this can jeopardise the value of the whole system.

Changes in coding systems between one period and another can result in serious discontinuity of the data to be linked, making comparisons over time problematic.

A future linkage framework should be sufficiently flexible to allow rapid linkage, for example to enable an urgent look-back exercise to take place in cancer screening or a BBV iatrogenic risk assessment

3. Are the guiding principles sufficient and appropriate? Please explain your answer fully and make suggestions for improvement.

Yes, they are sufficient and appropriate No, they are not

Please explain your answer fully and make suggestions for improvement.

4a. Are the objectives set out for a Privacy Advisory Service in Section 3c the right ones?

Yes, the objectives are right

No, they are not

Please explain your answer fully and make suggestions for improvement.

We think the Privacy Advisory Service would be very useful. The first four objectives are about providing data custodians and researchers with advice and help. The fifth is about demonstrating high standards of decision making. This suggests that the Advisory Service will also be making decisions about data linkage applications. It should be made clear whether or not the Advisory Service will be adjudicating on applications for data linkage or only providing advice and assistance in preparation for such adjudication by other bodies.

4b. Do you wish to be consulted on firmer proposals for a Privacy Advisory service as and when they are developed?

Yes No

5a. Are the functions that will be led by the National Data Linkage Centre set out in section 3d the right ones?

Yes, they are the right functions

No, they are not

Please explain your answer fully and make suggestions for improvement.

We think that the proposed Centre will be very useful and agree with all the functions listed.

It is not clear whether the proposed Centre would also act as an archive of linked datasets. This would seem a necessary function to guarantee the security and data integrity of any linked datasets whilst making them accessible to as wide a range of appropriate researchers as possible.

In many instances, data linkage will not be a single process: after the initial linkage, data for one or more of the linked data sets may require to be updated as new data become available. Without this function, the value of the linked data sets will be diminished.

5b. Do you wish to be consulted on firmer proposals for a National Data Linkage Centre as and when they are developed?

Yes No